

# STATE OF NEW YORK

5927--A

2021-2022 Regular Sessions

## IN SENATE

March 23, 2021

Introduced by Sens. HOYLMAN, RIVERA, BIAGGI, BRISPORT, BROUK, COMRIE, COONEY, HARCKHAM, HINCHEY, JACKSON, KAVANAGH, LIU, MANNION, MAY, MAYER, MYRIE, PERSAUD, RAMOS, REICHLIN-MELNICK, SALAZAR, SANDERS, SERRANO, STAVISKY -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the public health law, in relation to enacting the New York State COVID-19 Health Registry Act

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Article 21 of the public health law is amended by adding a new title 9 to read as follows:

### TITLE 9

#### New York State COVID-19 Health Registry

#### Section 2185. Legislative findings and purpose.

##### 2185-a. Definitions.

##### 2185-b. New York state COVID-19 health registry.

##### 2185-c. Enrollment and eligibility.

##### 2185-d. Confidentiality.

##### 2185-e. Annual report.

§ 2185. Legislative findings and purpose. 1. The legislature hereby finds, determines and declares that COVID-19 has had a devastating impact on the state of New York. Since the first recorded death of a New York resident from the virus on March fourteenth, two thousand twenty, tens of thousands of New Yorkers have lost their lives to COVID-19, and over one and a half million confirmed cases have been diagnosed as of the effective date of this article. The sudden emergence and rapid spread of COVID-19 around the world has led to an evolving understanding of the transmissibility, virulence, and symptoms of the virus by scientists and public health experts that continues to this day. Questions

EXPLANATION--Matter in italics (underscored) is new; matter in brackets [-] is old law to be omitted.

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1 remain as to why approximately eighty percent of those infected with  
2 COVID-19 experience mild to no symptoms, while the remainder experience  
3 a more severe response that can result in hospitalization or death, and  
4 weeks-long recoveries for those who survive. There is also growing  
5 awareness and concern about post-COVID conditions, sometimes referred to  
6 as "long COVID," in which a small but significant percentage of patients  
7 experience persistent symptoms weeks or months after recovering from  
8 their initial infection.

9 It is vital that the state of New York commit to monitoring and track-  
10 ing the long-term health impacts of COVID-19, even as effective vaccines  
11 become more widely available. The establishment of a voluntary registry  
12 of New Yorkers who survived COVID-19 infection holds the promise of  
13 providing public health experts with a database of information that may  
14 lead to a better understanding of trends in long-term illness and recov-  
15 ery, and the needs of survivors, particularly those suffering from  
16 post-COVID conditions.

17 § 2185-a. Definitions. As used in this title:

18 1. "COVID-19" means infection with or the disease caused by the severe  
19 acute respiratory syndrome coronavirus 2 (SARS-CoV-2);

20 2. "Registry" means the COVID-19 health registry established by this  
21 title.

22 § 2185-b. New York state COVID-19 health registry. The department is  
23 hereby authorized and directed to establish a voluntary statewide  
24 COVID-19 health registry for the purpose of monitoring the long-term  
25 health impacts of the virus. The registry shall serve, and shall be  
26 administered consistent with, the following public health purposes:

27 1. Monitoring the long-term physical and mental health impacts of  
28 COVID-19 infections, including, but not limited to, post-COVID condi-  
29 tions;

30 2. Periodically surveying registry enrollees to gather relevant infor-  
31 mation for the purposes of monitoring the long-term physical and mental  
32 health impacts of COVID-19 infections;

33 3. Sharing, subject to the confidentiality requirements of section  
34 twenty-one hundred eighty-five-d of this title and any other applicable  
35 state or federal laws or regulations, de-identified survey data or other  
36 registry information with researchers for the purpose of medical, public  
37 health or other scientific research. As a condition of sharing such data  
38 or information, any subsequently published studies, reports or findings  
39 that used such data or information shall be made available at no charge  
40 to the public on the department's website; and

41 4. Providing enrollees with information about COVID-19-related health  
42 studies, programs, benefits, and other relevant information.

43 § 2185-c. Enrollment and eligibility. 1. The initial enrollment period  
44 for the registry shall begin ninety days after the effective date of  
45 this section. The commissioner may set a date upon which the initial  
46 enrollment period ends, but such date shall not be prior to one year  
47 after the initial enrollment period begins.

48 2. The commissioner may, at his or her discretion, order additional  
49 enrollment periods subsequent to the initial enrollment period, of such  
50 lengths as he or she determines.

51 3. The commissioner shall promulgate regulations to establish eligi-  
52 bility for enrollment in the registry. Eligible participants shall, at a  
53 minimum, include New York residents who receive a diagnosis of post-CO-  
54 VID conditions made by an individual licensed to provide health care  
55 services within the state of New York.

1     § 2185-d. Confidentiality. 1. All registry information shall be kept  
2     confidential by the department and may not be disclosed except for a  
3     permitted purpose.

4     2. The commissioner shall promulgate regulations establishing permit-  
5     ted purposes and uses of registry information.

6     (a) All such regulations shall maintain the anonymity of individuals  
7     enrolled in the registry and govern access to information maintained by  
8     the registry.

9     (b) It shall not be a permitted purpose for the department or any  
10    authorized user of the registry to provide information contained in the  
11    registry with immigration authorities.

12    3. The registry shall comply with all state and federal laws and regu-  
13    lations related to maintaining the privacy and confidentiality of  
14    records contained with the registry.

15    § 2185-e. Annual report. The commissioner shall submit on or before  
16    December first, an annual report to the governor and the legislature  
17    concerning the operation of the registry. The first such report required  
18    under this section shall be published on December first of the calendar  
19    year following the commencement of the initial enrollment period for the  
20    registry, and shall include strategies for implementation of the regis-  
21    try and for promoting the registry to the general public, with a partic-  
22    ular focus on eligible enrollees belonging to racial or ethnic groups  
23    that have been disproportionately impacted by the COVID-19 pandemic.  
24    Subsequent annual reports shall include the findings of any surveys  
25    conducted by the department of registry enrollees, the findings of any  
26    scientific studies, papers, or reports produced using data or informa-  
27    tion collected in the registry, and recommendations for state action to  
28    address health issues or trends identified by the department.

29    § 2. This act shall take effect on the ninetieth day after it shall  
30    have become a law.